

Identifying the needs of kidney transplant recipients that can be addressed by a web-based self-management program

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Background: Kidney transplantation improves the quality of life (QOL) of patients with end-stage renal disease, however, post-transplant recovery of physical health and other aspects of QOL remain well below age- and sex-matched norms. While members of the health care team are focused on optimizing the biological responses to transplant, patients may have few or no tools at their disposal to engage in behaviours that optimize QOL. **Objective:** We aimed to identify the needs of kidney transplant (KTx) recipients that are appropriate to address through self-management. **Methods:** We used four strategies to identify areas of concern post-kidney transplantation: 1) a pilot study that used the patient-generated index to identify areas of QOL that are affected post-transplant, 2) review of the outcome domains suggested by the Standardized Outcomes in Nephrology-Transplantation (SONG-Tx) international initiative, 3) review of the domains included in QoL questionnaires for KTx recipients and patients with chronic kidney disease and 4) focus groups and key informant interviews with patients, clinicians, and researchers. We linked the identified themes to the International Classification of Functioning's code list and created a saturation table to visualize the most common areas of concern.

Results: The most prevalent identified topics (identified in ≥ 3 strategies) were physical activity; fatigue; pain; sleep; mental health; nutrition; sexual function; medication adherence; heart and kidney health. **Conclusion:** KTx recipients have many areas of concern post-transplant. The next steps will include the development of a comprehensive, evidence- and experience-based self-management program tailored to this patient population to improve their QOL.